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Testimony in Opposition to Proposed Budget Cuts to DPH-Funded
Children and Youth with Special Health Care Needs

Honorable Committee Members:

My name is Alix Mury and I am an employee of Family Centered Services of CT, Inc. I would like to strongly oppose proposed budget cuts to the DPH-funded CT Medical Home Initiative for Children and Youth with Special Health Care Needs program.

Children and Youth with Special Health Care Needs (CYSHCN) are children and youth age birth-21 who have, or are at increased risk for, a chronic physical, developmental, behavioral, or emotional condition and also require health and related services of a type or amount beyond that required by children generally.

The 2009/2010 National Survey of Children with Special Health Care Needs (CYSHCN) estimated there are approximately 139,453 children in Connecticut, ages 0-17 that have a special

health care need. This represents approximately 16% of all children in Connecticut who are in the 0-17 age range.

DPH currently funds five (5) care coordination contractors that provide care coordination services in support of pediatric practices that service CYSHCN within the state. Care Coordinators link children and youth with special health care needs and their families/caregivers to services and resources beyond the primary care site and even beyond health care, ensuring collaboration with schools, mental health services, social services, and other community based programs.

Family Centered Services (Family CT) has been providing DPH-funded care coordination free to low income children and youth with special health care needs and their families/caregivers since July 2007, and has provided coordinated care to more than 2000 children and youth and their families. We work to link children, youth and families with services and resources in a coordinated effort to optimize health outcomes and improve quality of care.

Care coordination for CYSHCN is complicated because there is no single entry point to multiple systems of care. Services provided to children, youth and families typically include:

- Providing assessments and monitoring of child and family needs
- Offering supportive services including counseling, education and listening
- Facilitating communication among the primary care physician, family and others
- Developing, monitoring, updating and following up with care planning and care plans
- Organizing wrap around teams with families

- Supporting meeting recommendations and follow-up
- Coordinating inter-organizationally
- Advocating with and for the family (e.g. to school, daycare, or health care settings)
- Finding, coordinating and promoting effective and efficient use of current resources
- Monitoring outcomes for child, family and practice and other activities needed and/or requested by the child and family.

Care coordination services are provided to the most medically and behaviorally complex children and youth, whose parents are often overwhelmed with their care and the care of their siblings as they struggle to deal with a complicated and fragmented system of services and supports. If any of you have a child with medically complex needs, you know the effort it takes to make sure that you do everything in the home you can to assist your child while also ensuring that all providers are talking to each other and on the same page, that test results are sent to the appropriate involved doctors, that you receive all the information you need, that PPTs are scheduled, that medications and equipment are ordered, transportation is made available...and the list goes on and on. Care Coordinators support families in these efforts and act as the organizing agent to make sure that everything takes place to serve the best interests of the child and the child's health and wellbeing.

We currently have three Care Coordinators who have caseloads of 30 children each and we have a waitlist of 40. Cutting these services would break the back of a system that is already sorely underfunded and understaffed. It would remove vital services and supports from families. Our

goal is optimal health for all children and this goal would certainly be undermined by the reduction of these services.

Thank you for your consideration. I appreciate the challenges you face in your deliberations and am happy to provide more information at any time.

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